# **Iowa Autism Council**

Wednesday, January 7, 2009 Facilitator: Mark Wolak/Sue Baker

#### **Present:**

Lana Michelson, Barb Rankin, Sue Baker, Mark Wolak, Katherine Byers, Joshua Cobb, Becky Flores(sitting in for Bill Gardam), Keith Gatrost, Becky Harker, Kenda Jochimsen, John Kohles, /Steven Muller, Jim Mumford, Grace Percival, Dr. Jeanne Prickett, Danielle Sharpe, Barbara Stineman, Dr. Charles Wadle, Dr. Debra Waldron, Patrick(Casey) Westhoff, Cathy Young Sonia Lewis

Absent: Dr. Ghada Hamdan-Allen, Pamela Parker

**Speakers:** Zeke Furlong from Dem Staff (Sent on behalf of Ray Zirkelbach) and Senator Beall

### Welcome/Public Comment: Josh Cobbs/Mark Wolak

Josh welcomed everyone to the meeting. The council had the opportunity to listen and ask questions of Zeke Furlong and Senator Beall regarding the Autism Insurance bill that the council supports. The council had an opportunity to review both the house and senate bill and to write down their questions prior to the meeting. Josh indicated that he did forward those questions to both Representative Ray Zirkelbach and Senator Beall prior to the meeting. The council decided to meet and discuss this bill further and determine if this will be a bill that the council supports.

NOTE: on January 21, 2009 at 12:00 the council met to vote on the recommended changes to the Autism Draft Insurance Bill. Those in attendance were, Josh Cobbs, Chuck Wadle, Barb Stineman, Cathy Young, Grace Percival, Casey Westhoff, Danielle Sharpe, Katie Byers, Steve Muller, Sue Baker, Lana Michelson, and Barb Rankin were in attendance to give guidance to the council. The members looked at each proposed change and each member gave their opinion on the language in the draft bill. Josh stated that the council's recommendations would not hinder the bill.

After much discussion, the council voted to accept the bill with the changes. The vote was 8 yes, 0 nay, and 1 abstain. Josh and Danielle will send a letter to Senator Beall and Representative Zirkelbach letting them know that the council voted to support the bill. There was a motion to adjourn the meeting. It was moved and seconded.

# Order of Business: Josh Cobbs/Mark Wolak

Josh asked the council to review the report to Governor Culver, which indicated what the council was working on. There was a motion to approve the report and the vote was unanimous. Josh indicated that the council needed to confirm the chair and co-chair. There was a motion to approve the chair and co-chair and the vote was unanimous on both. The minutes were approved with an unanimous vote.

# Review/Refine: Josh Cobbs/Mark Wolak

Barb R. went over the summary of the council's list of seven priorities of unmet needs. At the last meeting, the council was asked to prioritize (a-i of the law) which ones they wanted to work on first. The results are as follows: a) early identification etc., g) enhancing of community agency responsiveness etc., and h) finance options etc. were the first priority (this had the most votes as number 1), c) integration and coordination of the medical community, educators, healthcare etc., and h) financing options tied for second choice. Barb then looked at the most votes for first and second priority and the order would be h) finance options etc, a) early identification etc., and c) integration and coordination of the medical community, educators, healthcare etc. Everyone's third priority was h) finance options etc, b)appropriate early and intensive intervention services etc., and a tie for a) early identification etc. and f) training for educators, parents, siblings, and other family members.

Josh asked the council to take a few moments and discuss which one of the priorities they wanted to focus on. Danielle suggested that the council take on a and h and then look at choosing one of the others (g) enhancing of community agency responsiveness etc., c) integration and coordination of the medical community, educators, healthcare etc., b)appropriate early and intensive intervention services etc., and f) training for educators, parents, siblings, and other family members) as the third priority. The council discussed the priorities and which ones to start with. Lana stated that c) integration and coordination of the medical community, educators, healthcare etc. should be the umbrella to a) early identification etc. and h) financing options. This way, you will be thinking about integration as you look at c) integration and coordination of the medical community, educators, healthcare etc.

These categories will be looked at in subcommittees. There was another suggestion that as the council looks at the priorities, they should have some frame work in mind such as a program called "STEEEP" (Safe, Timely, Efficient, Effective and Equitable Patient centered) which is recognizable by the medical community. A motion was made to accept *c) integration and coordination of the medical community, educators, healthcare etc.* as the third priority that the council would work on. The vote was unanimous.

Mark commented on how well Josh was doing as chairperson. The council agreed with Mark and gave Josh a round of applause. Mark asked the council to think about the system that the council is participating in as a really large ocean liner or a whale (metaphorically) and you can't turn it and the council is like a school of fish with each one at times wanting to lead.

One of the challenges is to keep everyone in the room, because most people will vote with their feet. If you are not engaged or getting your needs met, and we don't hear it, then you won't come to the next meeting. The council will wonder "why" you are not here. Mark wants everyone to be careful that the council hears what your needs are. Even if you think others will not accept it.

Keep in mind that difference of opinions is a good thing and can be either constructive or destructive to the purpose of this council. Keep in mind that your need has to met. The council is driving a really large ship and it cannot be turned fast, you want to turn it fast and if you turn it fast, there will be a problem. The ship has to keep moving to keep government running to keep all these programs running for children and families.

Mark will be sending the council an article called the Neurology of Leadership. It is about how strong our emotions are tied to our thinking. If you are walking around with a specific belief, it's very hard to change your mind about it. The only way to change your mind is if you get an insight. Therefore, you have to be opened to insight.

The council had an open discussion about the draft of the By-laws. Josh asked the council to make any notes or revisions that they would like to see and then to e-mail those changes to him in a week or so and he would include those changes in the draft. The council did not make a final approval of the By-laws. It was motion and moved to close the discussion on the by-laws. The vote was unanimous.

#### Report Out Subcommittee activities: Josh Cobbs/Mark Wolak

Chuck stated that the subcommittee (Chuck, Steve, Grace, and Kathy) on ASD survey anticipated that a lot of the questions would not be answered and some of the ex-officio's made it very clear that some of the questions did not pertain to their agency. This is part of what the subcommittee wanted to identify. Chuck indicated that the survey could be an ongoing tool in the future to try and track things that are not being tracked now.

Chuck stated that the subcommittee discussed what information they were trying to capture and why. The goal was to get some kind of ideal of what services are available and who is getting those services (what ages, population, etc...). The group went over several questions, some wanted more details than others on the committee. The committee also thought that this survey could be a baseline for future surveys to track where resources and needs in the state are.

The committee wrote out the survey and each committee member kept a copy of the survey. Chuck had a staff person put the survey on an Excel spreadsheet for future use. The survey was distributed to the ex-officio's and Chuck had hard copies of the survey and the responses. These were placed on the handout table for those that wanted to review them. Chuck encouraged any ex-officio that had not responded to the survey, to do so even if the questions do not pertain to your agency.

Just explain what your department does and how that may or may not pertain to autism. The ex-officios that did respond were, the Department of Education, DHS, and Vocational Rehab. Josh felt that it was best to discuss how the process could be improved.

Lana stated when you look at the survey, the first question is "which of the following services does your agency provide?" The Department of Education looks at that as a direct service question. The Department of Education doesn't provide direct services to children. AEAs provide some direct services to children; the school districts provide direct services to children.

Lana stated that she was not sure of what the committee wanted to know or what question they were trying to answer or what information they wanted. She could have said, does the Department of Education provide behavioral consultation to families? The answer would be no. Does the Department of Education provide direct behavioral training to consumers? Who is the consumer, parents, families, generally speaking no, AEAs and school districts with families, the answer would be yes.

Dr. Waldron stated that the Department of Public Health doesn't provide direct services. They do contract with other agencies that do provide direct services and then the Title V funding comes to the Department of Public Health (CHSC) and yes they do provide some services. The Department of Public Health didn't answer the questions because they couldn't determine what information the committee wanted.

Josh stated that when he saw the survey, he stated that these were questions that he wanted the answers to. However, after talking with Lana a little more about the discussion points, he understood the frustration with the questions. Josh felt that this was a great learning experience for the council and the subcommittee. Josh stated that the council will still need data, and still need to know the population that is served.

The council will have to get the information in another way. He also recommends that this subcommittee stay in effect. Dr. Waldron stated that there wasn't any space for her to note what services/funding the Department of Public Health does provide. She would like to see space to put in clarification or state what services each agency does provide; this would be very helpful.

Josh stated that it may be a good idea to include some of the ex-officios in the subcommittee. They could help to revise the survey a little. It was suggested that each person put together a presentation and something in writing that will tell this council what/how the agency services relates to the council's objectives.

Once the council has been educated on how these different pieces fit together, the council will be better able to recognize how difficult it is to hold together these different groups. Lana stated that if you use the charge of the council (a-i) as the organizational structure, for talking about organizations, this would give some common structure for the presentation/written documentation to share with the council.

This was discussed at the last meeting; get this information from the agency ex-officios so that the council understands what's being done, what the agencies see as the successes,

and the areas for improvement. This would be countered by members of the council who are dealing either professionally or through families with Autism Spectrum children, so that they can bring their experiences and began to see where the gaps are.

The council discussed doing a public survey or focus group to obtain feedback and data about Autism disorders. It was suggested by Josh that if the survey was sent via e-mail that everyone use the same language (i.e. are you receiving services? Have you been denied services? etc...).

The data/information that the council wants should conform to the work (a-i). Josh stated that the council agrees that they need to get the data and needs to define what the council is asking for and get it to the right people.

#### Wrap up:

Mark give the council a process evaluation form for everyone to complete which will give the council guidance before the next meeting. Josh stated that there will be four subcommittees, and to keep in mind that a subcommittee cannot be more than six people. A member can be on as many subcommittees as they like.

The first subcommittee will be the legislative committee which will work on the autism draft legislation. Subcommittee members will be Josh, Danielle, Katie, Lana, Chuck, and Steve.

The second subcommittee will be to tackle the letter "a" which is "early identification by medical professionals of autism, including education and training of health care and mental health care professionals and the use of best practice guidelines". Subcommitte members are Deb, Sue, John, Lana, Josh and Grace.

The third subcommittee will be "c" which is "integration and coordination of the medical community, community educators, childhood educators, health care providers, and community-based services into a seamless support system for individuals and their families". Subcommittee members are Cathy, Barb R., Danielle, Deb, Barb S., and Bill.

And the fourth subcommittee will be "h" which is "financing options including but not limited to medical assistance waivers and private health insurance coverage". Subcommittee members are Chuck, Casey, Josh, Jim, Steve and Katie.

Josh wants each subcommittee to pick a chairperson during their first meeting. Josh will be sending a e-mail reminding everyone which subcommittee they are on.

# **Next Meeting:**

April 29, 2009 Stoney Creek Inn Johnston IA